

# Qualitative research with people who have a diagnosis of dementia

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# Qualitative Research with People Who Have a Diagnosis of Dementia

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The word 'dementia' comes from the Latin *demens* and is used as a hypernym to refer to symptoms such as memory loss, visual and auditory hallucinations, and changes in mood and personality that are typically associated with conditions such as Alzheimer's disease. As the number of people living with dementia has increased across the world, understanding dementia has become a more central priority within qualitative research. This entry provides a summary of the key intellectual movements that have shaped the development of qualitative research into dementia, before going on to discuss methods used to engage people with dementia in the research process and the ethical considerations that researchers need to navigate in so doing.

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## Dementia & Its Impacts

Whilst not a natural or inevitable part of ageing, the onset of dementia is strongly associated with biological age, as the likelihood of developing dementia-related conditions increases progressively after the age of 65. However, whilst the vast majority of people with dementia develop symptoms in their third and forth age, approximately five per cent of all those diagnosed are thought to be aged under-65.

In line with global population ageing, the number of people living with dementia has

increased significantly over the course of the 21st century. According to research conducted by Alzheimer's Disease International and the World Health Organization, there were an estimated 46.8 million people living with dementia in 2015. In the absence of new disease modifying therapies, the global population of people with dementia is expected to reach 131.5 million by the middle of the 21st century, with much of the growth occurring in low and middle income countries (Alzheimer's Disease International 2015).

The rise in the number of people living with dementia has brought increased awareness from governments, research councils, health and social care organisations, the media and the general public, of the impact that dementia has on individuals, on communities and on health and social care systems. In the United Kingdom, for example, dementia was estimated to have cost £26 billion in the year 2014, with approximately two thirds of costs shouldered by those affected, largely through the provision of unpaid familial care (see: Prince et al. 2014). In addition to financial burdens, a diagnosis of dementia often has devastating psychosocial impacts for individuals and their families.

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# Dementia: An Historical Overview

Whilst the focus on dementia increased significantly following the turn of the 21st century, researching dementia can be traced back to the European Enlightenment and the development of the 'moral treatment' movement. Inspired by the philosopher John Locke (1632-1704), pioneers in the humane care of 'the insane' - such as Philippe Pinel (1745-1826) in France and William Tuke (1732-1822) in England - first conceptualised dementia as

the *abolition* of the reasoning faculties. This represented a significant break from conventional wisdom, which tended to associate 'insanity' with the fall into animality. As such, moral treatment represented the first, distinctly modern approach to understanding dementia.

The rise of biomedicine in the late 19th and early 20th centuries, however, saw a shift in understandings of dementia, away from corruption of the reasoning faculties and towards understandings grounded in physiological explanations. Correspondingly, understanding the lived experience of dementia came to be seen within biomedicine as of secondary importance to understanding dementia's disease pathology.

By the end of the 20th century, the lack of attention to the lived experience of dementia within biomedicine, came under fierce criticism. Influenced by the emerging disability movement in the 1980s, researchers such as Karen Lyman (e.g. 1989), Tom Kitwood (e.g. 1997), and Stephen Sabat (e.g. Sabat & Harre 1992), developed strong critiques of the biomedicalisation of dementia and of biomedicine's disabling effects. Thus, the rise of a new, *Personhood* movement in dementia during the early 1990s, brought with it a renewed interest in qualitative approaches to dementia, especially in exploring how everyday social interactions in dementia may facilitate, or inhibit, the maintenance of a positive sense of self.

The early 21st century saw increased recognition of dementia as a social and political issue, in addition to a personal one. With the rise of organisations such as the Scottish Dementia Working Group (SDWG) - a campaigning organisation run by-and-for people with a diagnosis of dementia - the status of dementia as a socially maginalised and stigmatised category within society became much more widely recognised within policy making. Alongside this shift towards more rights-based and social citizenship inspired understandings

of dementia, research came to devote more attention to exploring the *voice* of people living with progressive neurocognitive conditions and to developing new ways of involving people with dementia in the research process.

# The Use of Qualitative Methods in Dementia Research

As understandings of dementia have changed since the beginning of the 19th century, so to have qualitative approaches to dementia research. Whilst *moral treatment*-based approaches essentially advocated the use of qualitative methods for positivist-inspired ends, the rise of the *Personhood* movement brought considerable emphasis on symbolic interactionist perspectives. Similarly, the turn towards rights-based understandings of dementia in the early 21st century, led to greater diversification within qualitative dementia research by incorporating participatory and action-orientated frameworks. As a result, qualitative dementia research in the 21st century is a broad church, within which the influences of several research traditions are visible, and where different methodological approaches lend themselves to particular methods for generating qualitative data.

## The Use of Observation

Originally advocated by Pinel as a central technique for understanding mental disorder, close observation remains a central method within qualitative dementia research - especially when researchers are looking to explore the lived experiences of people in the more advanced stages of dementia. The rise of the *Personhood* movement in the early 1990s saw renewed interest in the use of observation as a qualitative tool, with the introduction of *Dementia Care Mapping* [DCM]. As a structured observational tool used to assess the

quality of care experiences by paying close attention to micro-level social interactions, DCM has been used extensively within both dementia care practice and within qualitative dementia research across a range of health and social care settings, in particular research within care homes and hospital in-patient facilities. Whilst DCM was originally developed at the home of the *Personhood* movement at the University of Bradford, subsequent researchers have developed derivations of this method in order to enhance the amount of qualitative data that can be obtained through structured observation (see, for example, the *Person Interaction Environment Care Experience –Dementia* tool [Brooker et al 2011]).

Whilst structured observation is a central technique within person-centred qualitative dementia research, less structured approaches to observation are also widely employed, including ethnographic and participant forms of observation. In contrast to DCM, these forms of observation tend to involve the researcher becoming an active participant in the social world and care experiences of the person with dementia, with data collection usually taking place over a period of several weeks, or months. Although these two approaches to observation take qualitatively different forms, they can be used in combination; with, for example, structured observation being used to identify key issues and experiences that can subsequently be explored in-depth, and over a longer timeframe, using less structured observation techniques.

## The Use of Qualitative Interviewing

In-depth and semi-structured forms of interviewing are popular techniques within qualitative dementia research, as they have proved to be effective methods for exploring the inner worlds and subjective realities of people with dementia. In contrast to observation, the use of qualitative interviewing is less associated with applied dementia care research and is

often used as a way of generating insights into the illness narratives and personal biographies of people with dementia. Inspired in large part by the sociology of health and illness, with its emphasis on exploring the construction of illness narratives, in-depth interviewing has been used effectively to highlight the ways in which people with dementia make sense of their dementia journeys and re-construct a positive sense of self in the aftermath of diagnosis.

However, due to the cognitive demands that qualitative interviewing often places on participants, facilitating interviews with participants in the more advanced stages of dementia can be challenging. As a result, interviewing in qualitative dementia research often tends to be used more with people in the early and mid-stages of dementia, especially in the period following diagnosis. Whilst this is the case, researchers have sought to make the interview environment more accessible to people with more advanced-stage dementia through, for example, the use of walking interviews and *Talking Mats* to facilitate communication, and by incorporating emotional touchpoints and visual inquiry techniques to aid discussion on more emotive issues (see, for example, Dewar, Mackay & Smith 2009).

## The Use of Arts-Based Approaches

Alongside more conventional social science research methods, arts-based techniques such as Photovoice, participatory theatre and participatory filmmaking, have become established within qualitative dementia research. Whilst the use of methods such as interviews and observation tend to be aligned with phenomenology and symbolic interactionist frameworks, the rise of arts-based approaches is primarily a result of the emergence of participatory and action-orientated methodologies within qualitative dementia research. The use of arts-based approaches first emerged in dementia care, as opposed to qualitative dementia research, as health and social care organisations started to incorporate

mediums such as drama, music, dance and clowning within care settings, as a means of improving health outcomes and promoting wellbeing amongst people with dementia. However, researchers working from more participatory and action-orientated perspectives, have been drawn to the use of arts-based methods as a means of addressing some of the limitations associated with more established qualitative data collection techniques. The quality of data derived through methods such as qualitative interviewing, for example, tends to rely upon participants' high-order cognitive and verbal abilities (such as reflective thinking, recall, diction and narration). This, it has been argued, risks positioning people with dementia as *less capable* of participation in qualitative research, which can re-enforce a sense of stigma in dementia and fails to fully hear the person's voice. By using arts-based techniques underpinned by what Jocey Quinn and Claudia Blandon (2017) refer to as 'beyond words' methodologies, researchers working from this tradition have sought to develop more embodied, affective, and transformative approaches to researching dementia.

## The Use of Online Approaches

As availability and sophistication of digital technologies has increased dramatically since the turn of the 21st century, more people with a diagnosis of dementia are using the internet to establish communities and communicate experiences. This is especially the case amongst people diagnosed with 'early onset' dementia (i.e. symptoms pre-65 years of age). As a consequence, global social media platforms such as *Twitter*, *Wordpress* and *Facebook* have become rich sources of qualitative data for dementia research in the 21st century. However, whilst online platforms can provide new insights into everyday experiences and communities in dementia, these tend to produce distinctly digital forms of data that, arguably, *offline* approaches to qualitative research may be ill-equipped to address. Bronwen Thomas

(2017) for example, argues that online dementia narratives communicated via Twitter, challenge the 'coherence paradigm' within narrative studies, which tends to assume that coherence is a necessary ingredient for telling stories about health, illness and self-identity. As a result, Thomas argues that more *netnographic* approaches to dementia research are needed, in order to fully understand the relationships between self, illness and identity that are expressed through the often partial and fractured nature of online narratives.

# Ethical Considerations

Conducting qualitative research in dementia can be a challenging endeavor, as researchers are often required to address a number of practical and ethical considerations in order to gain approval from research ethics committees. One of the central ethical issues surrounding the involvement of people with dementia in research is the extent to which participants may have the capacity to give, or withhold, their informed consent to participate.

Conventional approaches to obtaining informed consent, such as providing participants with detailed information sheets and asking them to sign consent forms, are often not the most appropriate nor accessible mediums for consenting people living with dementia. However, rather than excluding people with dementia from research on the basis of capacity, qualitative researchers have sought to develop alternative procedures for establishing the presence of consent (and its absence) that are better suited to the dementia research environment.

Jan Dewing (2007) for example, argues that researchers need to adopt a *process model* of consent-seeking when involving people with dementia in research. In contrast to conventional approaches, which stress the importance of written consent at the outset, the

*process* model of consent involves the researcher seeking to establish and re-establish consent throughout data collection and in ways combatable with the individual's needs and abilities. As a result, researchers following process models of consent, are often required to first spend time getting to know the person with dementia, ahead of any attempt to establish consent, and exploring with the person and with those closest to them, the most appropriate means of gauging consent.

Process models of consent-seeking tend to be founded upon relational ethical frameworks. Relational ethics posits that human capabilities and attributes, such as the ability to process information or to exercise individual autonomy, are shaped at least in part, by the social environment within which they are being assessed. Thus, how a person with dementia retains information in one environment may be qualitatively different to how they do so in other environments. As such, and in addition to getting to know the person with dementia, the onus is on the researcher to facilitate environments that are as enabling as possible for processes of seeking and giving consent. This may include, for example, engaging with the person at a time of day when they are known to be at their most alert, or most receptive to social interaction, as well as ensuring that distracting noises and background activities are minimized during the consent-seeking process.

Alongside process models of consent-seeking, researchers have also sought additional (or *proxy*) forms of consent from either the next of kin or the named representative of the person with dementia. Whilst this can be a valuable component in ensuring that research is conducted in an ethical manner, most qualitative researchers in dementia would argue that this is not a substitute for seeking the views and permissions of the person with dementia themselves.

## Core Principles for Involving People with Dementia in Research

With the rise of what Ruth Bartlett (2014) refers to as the *emergent modes of dementia activism,* people with dementia in the 21st century have become more involved in dementia research - not just as research participants, but as active collaborators, advisors and gate-keepers in the research process. As the volume of research into dementia has increased, some dementia activists have been critical of the ways in which researchers have sought to include people with dementia in the past. The Scottish Dementia Working Group (2014), created the *Core Principles for Involving People with Dementia in Research* in order to help shape ethical approaches to research that are informed by those whose expertise derives primarily from lived experience. Thus, led by people with dementia who have had extensive experience in participating in social and medical research, the core principles contain practical advice for novice and experienced researchers alike. Recommendations are ordered around six *core* principles and include: ensuring that people with dementia are informed as to the outcomes of the research, that research environments are fully accessible to people with dementia (both physically and cognitively), that researchers undertake appropriate and rigorous training in dementia *prior* to engaging with participants, and that researchers manage *time* in ways that are sensitive to how people's sense of time and linearity can be affected by the onset and progression of dementia.

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# Further Readings

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